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ABSTRACT

This report fccuses on the barriers to employment encountered by millions of individuals with disabilities and on proposals that would eliminate or reduce those barriers. The report describes the following three barriers: (1) many people would be worse off financially if they worked and earned to their potential than if they did not work; (2) people with disabilities cannot choose their own vocational rehabilitation program; and (3) people with disabilities lack employment opportunities. Fifteen action proposals are suggested to help people with disabilities overcome these barriers. The report concludes with a challenge to the 105th Congress to turn to people with disabilities to contribute to their country and to make their contributions more feasible through enactment of legislation based on the action proposals. (KC)

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REMOVING BARRIERS TO WORK: Action Proposals for the 105th Congress and Beyond

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NATIONAL COUNCIL ON DISABILITY

September 24, 1997

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Removing Barriers to Work: Action Proposals for the 105th Congress and Beyond

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NATIONAL COUNCIL ON DISABILITY

An independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.

LETTER OF TRANSMITTAL

September 24, 1997

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the members of the National Council on Disability (NCD), I submit this special report, *Removing Barriers to Work: Action Proposals for the 105th Congress and Beyond*, which focuses on the barriers to employment encountered by millions of individuals and on proposals that would eliminate or reduce those barriers.

The action proposals in this report represent what NCD sees as an emerging consensus in the disability community about the kinds of reforms needed to remove the major barriers preventing Supplemental Security Income recipients and Social Security Disability Insurance beneficiaries from becoming more self-sufficient through employment. These proposals are fully in line with your desire to "invest in the education and training of our people" and to "tackle the tough issue of entitlement reform . . . [by making] tough choices to strengthen and protect Medicare and Social Security over the long run." The proposals reflect the emerging bipartisan emphasis on personal responsibility by removing some of the complex and burdensome federal requirements that prevent many people with disabilities from taking charge of their own lives and becoming employed.

Social Security programs can be transformed from a lifelong entitlement into an investment in employment potential for thousands of individuals. With your help, Mr. President, these NCD proposals, which are a cost effective investment, will enable many people to fulfill the dream of the Americans with Disabilities Act.

We look forward to working with you as we seek to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Sincerely,

Marca Bristo

Marca Bristo
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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EXECUTIVE SUMMARY

This report by the National Council on Disability (NCD), an independent federal agency, focuses on the barriers to employment encountered by millions of individuals and on proposals that would eliminate or reduce those barriers.

More than 3.5 million people ages 16 to 64 who have disabilities receive Supplemental Security Income (SSI) benefits. Only 2.32 percent of these people are working and earning more than $500 per month, the earnings threshold for determining whether benefits will continue. Of the more than 4 million beneficiaries of Social Security Disability Insurance (DI), only 0.33 percent earn more than $500 per month after their 12 months of trial work and grace periods. Research and copious anecdotal evidence both demonstrate that many more SSI recipients and DI beneficiaries want to work; and with appropriate support, they are capable of working above the $500-per-month earning level.

The action proposals in this report represent what NCD sees as an emerging consensus in the disability community about the kinds of reforms needed to remove the major barriers preventing SSI recipients and DI beneficiaries from becoming more self-sufficient through employment. These proposals are fully in line with President Clinton's desire to "invest in the education and training of our people" and to "tackle the tough issue of entitlement reform [by making] tough choices to strengthen and protect Medicare and Social Security over the long run." The proposals reflect the emerging bipartisan emphasis on personal responsibility by removing some of the complex and burdensome federal requirements that prevent many people with disabilities from taking charge of their own lives and becoming employed.

Social Security programs can be transformed from a lifelong entitlement into an investment in employment potential for thousands of individuals. These NCD proposals are a cost effective investment that will enable many people to fulfill the dream of the Americans with Disabilities Act.

The proposals are the culmination of an intensive campaign to hear from consumers, advocates, and grassroots disability leaders, a campaign that began with the 1996 NCD national policy summit that produced the landmark report, *Achieving Independence*. Consumers and

advocates expanded upon the employment recommendations from that report during a 2½-day working conference in 1997. The 40 conference participants—most of whom are or have been SSI recipients or DI beneficiaries and all of whom are very knowledgeable about disability employment issues—identified barriers to employment facing individuals with disabilities and generated a series of proposals for overcoming those barriers. To find out what the rest of the disability community thought of the proposals, NCD took oral and written testimony from hundreds of individuals with disabilities, their families, and advocates through a series of 13 hearings around the country.

The disability community identified the following major barriers and the reforms needed to reduce them.

Barrier: Many People Would Be Worse Off Financially If They Worked and Earned to Their Potential Than If They Did Not Work

People fear most of all losing the medical benefits that can literally spell the difference between life and death. They fear a sudden loss of cash benefits when they earn a mere $500 per month—earnings too low to make up for the lost medical coverage or to pay for their disability-related work expenses, such as wheelchairs and personal assistants. According to Maynard Bostrom from Minnesota, "Now, you either stay under $500 or get a position that pays high enough to make it worth it," which the Employment Support Institute at Virginia Commonwealth University estimates to be more than $24,000 per year.

Many other people fear that if they work, the Social Security Administration (SSA) will declare them no longer disabled and therefore ineligible for further benefits, even though they have had no medical improvement. This fear is especially acute for those with conditions that are recurrent or relapsing, such as multiple sclerosis or long-term mental illness. They are afraid to take the risk if the probability of relapse or recurrence is high.

Finally, consumers fear the complexity and the apparent capriciousness of the rules that deny or allow them to keep some of their benefits while working. According to the National Academy of Social Insurance, SSA overpays approximately 75 percent of the beneficiaries who

earn between $600 and $1,000 per month. Because of staff shortages and lack of training or incentives, SSA itself seems unable to explain and administer these complex rules adequately.

All these fears are exacerbated for people who have or who want to have spouses and children. Consumers denounced the complexity and unfairness of counting a family member's income when determining benefits under SSI.

The action proposals to the 105th Congress to address these fears are summarized below.

PROPOSALS TO MAKE WORK PAY

Provide Medical Coverage for Workers With Disabilities

Congress should require States to provide Medicaid coverage like that currently available to SSI recipients to all DI beneficiaries who earn more than $500 per month. All DI beneficiaries and SSI recipients who earn more than threshold amounts set by the States would have to pay a fee (on a sliding scale) to keep their Medicaid coverage.

Replace the DI "Income Cliff" With Gradual Benefit Reductions

Congress should establish similar rules for SSI and DI that would give full benefits to those earning less than $500 per month and would reduce cash benefits by $50 for each $100 of earnings above that level. This would eliminate the "income cliff" faced by many DI beneficiaries who would see their disposable income plummet if they earned $500 or more per month.

Ensure That People Do Not Lose Eligibility Because They Work

Individuals whose SSI or DI cash benefits have stopped because of their earnings—but who have not medically recovered from their disabilities—should remain eligible for future benefits in the event that their earning ability declines. People with permanent disabilities should not have to repeat the arduous eligibility determination process every time their disabilities prevent them from working.

Congress should ensure that continuing disability reviews (CDRs) are carried out on schedule (every 3 or 7 years, depending on the disability) and are not triggered by an individual's engaging in work activity. Currently, individuals who work receive what they say are "intimidating and threatening" letters telling them that a CDR is being scheduled to see whether they have "recovered" from their disability. Instead, workers should get letters congratulating them for becoming employed and informing them about the work incentives they may find useful.

Compensate for Disability-Related Work Expenses

Congress should establish a tax credit that would reimburse individuals earning less than $50,000 per year for 75 percent of their disability-related work expenses. Individuals should get this refund even if they do not owe income taxes, either in a lump-sum check from the Internal Revenue Service or as an addition to each paycheck.

Remove Marriage Penalties

Congress should ensure that Social Security benefits are based on individual earnings and income. SSA should not penalize beneficiaries for being married or for being disabled adult children of disabled, retired, or deceased beneficiaries.

Waive No-Fault Overpayments

Congress should instruct SSA to collect SSI or DI overpayments only in cases of consumer fraud, failure to report changes in income, or intentional misrepresentation of income. Overpayment waivers should be granted routinely and quickly when SSA has made overpayments and the SSI recipient or DI beneficiary is not at fault.

Raise Resource Limits

Congress should raise the resource limits for SSI eligibility from $2,000 to $5,000 and exempt Super IRAs, qualified plans, and medical savings accounts from this resource

limitation. These plans allow tax-favored savings for education, medical emergencies, or retirement and should not affect SSI eligibility.

BARRIER: PEOPLE WITH DISABILITIES CANNOT CHOOSE THEIR OWN VOCATIONAL REHABILITATION PROGRAM

Consumers feel that they have insufficient access to and choice of the services and supports they need to prepare for, gain, and maintain employment or self-employment. Most SSI and DI applicants are never offered rehabilitation services. Those who receive the offer have only one choice in rehabilitation providers (the State vocational rehabilitation agency) and must wait for long periods to receive services.

Some individuals' disabilities will always prevent them from earning more than $500 per month. There are many more individuals, however, who could earn a significant amount and be much more (if not completely) financially self-sufficient. They could do so if the financial disincentives identified above were reduced and if they had access to and information to make choices about training programs, employment counseling, adaptive equipment and transportation, and, in some cases, resources needed to start their own businesses.

PROPOSALS TO INCREASE ACCESS AND CHOICE

Institute a "Ticket" or "Voucher" Program

Congress should create a "ticket" or "voucher" program that enables SSI recipients and DI beneficiaries to select and buy services leading to employment. Individuals should be allowed to choose from a wide array of service providers, including educational institutions, training facilities, job-coaching services, and assistive technology.

The tickets should be financed from the savings to taxpayers that result from individuals going to work and thus leaving the Social Security rolls. The tickets should provide sufficient reward to service providers to be an incentive for them to participate in the program.

Provide Access to Investment Funding

The Plan for Achieving Self-Support (PASS)—or a PASS-like program—which allows consumers to invest in training, equipment, or other assets needed for employment, should be retained, simplified, and made available to both SSI recipients and DI beneficiaries.

Eliminate the Scholarship Penalty

Congress should direct SSA to exclude all scholarship and fellowship income in determining both initial eligibility for SSI and cash benefit amounts for SSI and DI.

BARRIER: PEOPLE WITH DISABILITIES LACK EMPLOYMENT OPPORTUNITIES

People with disabilities face a daunting challenge when they try to find employment. They must not only overcome the limitations imposed by their disabilities, but also compete with recent high school and college graduates, the victims of industry downsizing and relocations, and all the welfare recipients who now must go to work.

Furthermore, many employers are reluctant to hire a person with a disability. Employers fear increased health insurance costs; the need to provide reasonable but possibly expensive accommodations; and the perceived need to deal with adverse reactions by customers, coworkers, and supervisors who might be uncomfortable around people with disabilities.

Employers' first fear, that they could face increased health insurance costs, would be alleviated by NCD's proposal for a Medicaid buy-in with wrap-around coverage. The other fears and the competitive realities are addressed by the next proposals.

PROPOSALS TO INCREASE EMPLOYER INCENTIVES

Reimburse Employers for Disability Expenses

Congress should institute a tax credit to reimburse employers for the expenses involved in providing employees with sign language interpreters, print materials in alternative formats,

on-the-job personal assistance, extraordinary training, job coaches, and other accommodations that are not funded by other sources.

Institute a Tax Credit for Disability/Diversity Training

Congress should enact tax credits for employers that conduct disability/diversity training for all personnel within the organization. The credit should be available only for 1 year after its establishment. This brief availability period would encourage employers to move quickly toward supporting disability awareness and a new focus on employing individuals with disabilities. The training should be conducted by professional trainers with disabilities.

In Conclusion

Over the past 15 months, NCD heard countless individuals with disabilities say that they want very much to work and that they would do so but for the barriers encountered when they tried. Those barriers and the action proposals designed to reduce those barriers are detailed in the report that follows. The findings and proposals are supported with testimony, explanations, and analyses using WorkWORLD software.[1]

NCD calls on Congress to take a hard look at what people with disabilities believe would allow them to work, earn to their potential, and contribute more fully to their communities and to society at large.

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[1] WorkWORLD is decision support software developed by the Employment Support Institute at Virginia Commonwealth University's School of Business. It helps analyze and illustrate the financial effects of alternative policy options.

INTRODUCTION

This report by the National Council on Disability (NCD), an independent federal agency, addresses the employment of people with disabilities and their experiences in trying to prepare for, gain, and maintain employment or self-employment. The report discusses the barriers encountered by a particular segment of the disability community: those who are receiving or who are eligible to receive benefits through the Disability Insurance (DI) and Supplemental Security Income (SSI) programs of the Social Security Administration (SSA). The report then presents NCD's proposals for eliminating or reducing those barriers, based on the input from the disability community.

More than 3.5 million people ages 16 to 64 who have disabilities receive SSI benefits. Only 2.32 percent of these people are working and earning more than $500 per month,[2] the earnings threshold for determining whether benefits will continue. Of the more than 4 million beneficiaries of DI, only 0.33 percent earn more than $500 per month once their 12 months of trial work and grace periods have expired.[3] Both research and copious anecdotal evidence demonstrate that many more SSI recipients and DI beneficiaries want to work; and with appropriate support, they are capable of working above the $500-per-month earning level.[4]

The action proposals in this report represent what NCD sees as an emerging consensus in the disability community about the kinds of reforms needed to remove the major barriers preventing SSI recipients and DI beneficiaries from becoming more self-sufficient through employment. These proposals are fully in line with President Clinton's desire to "invest in the education and training of our people" and to "tackle the tough issue of entitlement reform [by making] tough choices to strengthen and protect Medicare and Social Security over the long

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[2] Social Security Administration, Office of Research, Evaluation, and Statistics, Division of SSI Statistics and Analysis. *Quarterly Report on SSI Disabled Workers and Work Incentive Provisions*, June 1997.

[3] Data from an April 1996 analysis by the SSA Office of Disability for individuals under age 59.

[4] See the 1994 *N.O.D./Harris Survey of Americans With Disabilities* conducted by Louis Harris and Associates for the National Organization on Disability; and *Supported Employment Research: Expanding Competitive Employment Opportunities for Persons With Significant Disabilities*, edited by P. Wehman, J. Kregel, and M. West (Richmond, VA: Rehabilitation Research and Training Center, Virginia Commonwealth University, 1997).

run."[5] The proposals reflect the emerging bipartisan emphasis on personal responsibility by removing some of the complex and burdensome federal requirements that prevent many people with disabilities from taking charge of their own lives and becoming employed.

Social Security programs can be transformed from a lifelong entitlement into an investment in employment potential for thousands of individuals. These NCD proposals will enable many people to fulfill the dream of the Americans With Disabilities Act (ADA), while helping to balance the budget by saving taxpayers billions of dollars.

The NCD proposals are the culmination of an intensive campaign to hear from consumers, advocates, and grassroots disability leaders, a campaign that began with the 1996 NCD national policy summit that produced the landmark report, *Achieving Independence*.[6] Consumers and advocates expanded upon the employment recommendations from that report during a 2½-day working conference held in Houston in February 1997. The consumers and advocates who met in Houston—most of whom are or have been SSI recipients or DI beneficiaries and all of whom are very knowledgeable about disability employment issues—identified barriers to employment facing individuals with disabilities and generated a series of proposals for overcoming those barriers. (The participants in the Houston conference were aided in crafting many of the proposals by WorkWORLD, decision support software developed and facilitated by staff from Virginia Commonwealth University's Employment Support Institute (ESI). Included in this report are WorkWORLD analyses that demonstrate the impact of many of the proposals on individuals who go to work.)

NCD then disseminated those proposals widely, including posting them on the World Wide Web, and held a series of 13 hearings around the country to find out what the rest of the disability community thought of the proposals. NCD took oral and written testimony from hundreds of individuals with disabilities, their families, and numerous advocacy and service provider organizations. In publicizing and conducting theses hearings, NCD made a special effort to ensure that underrepresented communities—such as Hispanics, African Americans, and Native

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[5] Quotations are from President Clinton's opening remarks at his press conference held on August 6, 1997.

[6] The NCD report's full title is *Achieving Independence: The Challenge for the 21st Century—A Decade of Progress in Disability Policy—Setting an Agenda for the Future*. (July 26, 1996).

Americans—had a chance to review and comment on the proposals. For example, one hearing was held in Spanish. NCD also ensured that a wide range of disabilities were represented.

The testimony included statements from policy experts, leaders of local and national disability organizations, and many grassroots individuals who had their own stories to tell. The overall intent of these hearings and proposals was perhaps best summed up by a 14-year-old with Down syndrome who said,

> *When I grow up, I want to be a firefighter. If there is a house on fire, I will help to squirt out the fire. I want to live in my own apartment. I will need a job to pay for the apartment. I will need a job to pay for food and clothes. Rules about working should be easy. Rules should help me get a job.* (Tiffany Zimenoff, Boulder, Colorado)

Rules should not be barriers to employment. Rules should help Tiffany and others get jobs. The current rules governing DI and SSI benefits often do not help. The following section of this report describes the major barriers to employment identified by people with disabilities and their advocates—explaining why so few people with disabilities go to work and lessen their dependence on DI and SSI benefits—and offers proposals for change.

BARRIERS AND ACTION PROPOSALS

Barrier: Many People Would Be Worse Off Financially If They Worked and Earned to Their Potential Than If They Did Not Work

People fear, most of all, losing the medical benefits that can literally spell the difference between life and death. They fear a sudden loss of cash benefits when they earn a mere $500 per month—earnings too low to make up for the lost medical coverage or to pay for their disability-related work expenses, such as wheelchairs and personal assistants. Many people also fear being denied medical benefits in the private sector because of preexisting conditions. According to Maynard Bostrom from Minnesota, "Now, you either stay under $500 or get a position that pays high enough to make it worth it," which the Employment Support Institute at Virginia Commonwealth University estimates to be more than $24,000 per year.

An individual with a chronic respiratory condition said,

> *Giving up SSI, SSDI, food stamps, and perhaps rent subsidy is a risk worth taking. Giving up health coverage is actually life-threatening.* (D.C. Brown, Seaford, Delaware)

Many people also fear losing their cash benefits at earning levels too low to make up for the benefit loss. A supported employee of a Vermont Wendy's who lost her job because she could not work enough hours commented,

> *It is always said that there are incentives for us to go to work, but in reality there can be consequences to work, such as loss of some benefits or risk of losing them if your employer even asks you to stay an extra hour. I feel their incentives are not really fair! I feel if there was less threat of losing benefits, etc., that you would see*

a lot more people willing to return to work with the help of Supported Employment. I would love to find a job and not be afraid of losing my benefits.
(Lisa Fairbrother, Newport, Vermont)

Lisa could not work as many hours as her employer wanted because doing so would have caused her to lose her DI and Medicare benefits. She obviously wants very much to work, but the current structure of the DI program is the biggest barrier to her employment.

A man from Cloquet, Minnesota, who had sustained a back injury was helped by his vocational rehabilitation (VR) agency to return to college and become a licensed facility administrator. He said that he then could not find a job making enough money to compensate for losing his DI benefits. He has been offered and encouraged to accept assistant-level jobs at $12,000 per year, but he cannot afford to do so because he would lose his DI benefits and be much worse off financially. The higher-paying jobs, unfortunately, always demand the experience he cannot afford to get.

Many individuals also fear that their disability-related work expenses will so deplete their earnings that they will not be able to afford to work. The current impairment-related work expense (IRWE) provisions will reimburse SSI recipients who earn between $65 and $1,053 per month for up to 50 percent of the costs of their disability-related expenses.[7] Most individuals think that the variable IRWE reimbursement rate is both too low and too confusing. Although they would prefer that 100 percent of their disability-related work expenses be reimbursed, most of those who testified regarding the work-expense tax credit agreed that a straightforward 75 percent reimbursement would be far better than the current variable system.

Many others fear that if they work, SSA will declare them no longer disabled and therefore ineligible to restart their benefits without going through a new, lengthy, tedious application process if their earning ability should decline. This fear is especially acute for those

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[7] The actual reimbursement level depends on the gross earnings level and can range from no reimbursement at earnings of $65 per month to 50 percent reimbursement at earnings of $1,053 per month, for expenses up to $968 per month or $11,616 per year. Above the $1,053-per-month earnings level, the percentage of reimbursement declines at a rate dependent on the amount of expenses claimed.

with conditions that are recurrent or relapsing, such as multiple sclerosis or long-term mental illness. They are afraid to take the risk if the probability of relapse or recurrence is high.

For DI beneficiaries, this fear is realized if they earn more than $500 per month for even 1 month after they have completed their extended period of eligibility.

For SSI recipients, the first fear of losing eligibility arises from the fact that their earnings now trigger a continuing disability review (CDR). They say that many of their friends have been found through CDRs to have "recovered" from their disabilities, even though those friends are still using wheelchairs, respirators, and personal assistants to survive. The second fear of SSI recipients is that their earnings may exceed the thresholds for Medicaid eligibility, which vary from State to State and can even be set individually. In Arizona, for example, the 1996 threshold for household income was only $12,300 per year.

The president of the Vermont Psychiatric Survivors said,

> *Work activity should not trigger a CDR. Many consumers are frightened beyond words about a CDR and often will cease all work activity and pull away from their rehabilitation plan.* (Phil Wolf, Newport, Vermont)

Many of these fears are exacerbated for people who have or who want to have spouses and children. Consumers denounced the complexity and unfairness of counting a family member's income when determining benefits under SSI.

One couple, for example, spoke about the "marriage penalty" that caused one of them to lose Medicaid:

> *Many members of the disability community who want to marry believe that the threat of loss of Medicaid benefits, without the existence of universal health coverage, is a choice between love and death, life and loneliness.* (Barbara Waxman Fiduccia and Daniel Fiduccia, Cupertino, California)

When Barbara and Daniel married, they were both receiving SSI and Medicaid. When he got a job, he retained his Medicaid through the SSI 1619b provisions; but she lost hers because deemed income made her ineligible for SSI and Medicaid. The action proposal below concerning the elimination of the marriage penalty addresses this problem.

Finally, a majority of the consumers who testified said they fear the complexity and the apparent capriciousness of the rules that deny them or allow them to keep some of their benefits while working. They said that SSA seems unable, because of lack of staff or training or incentives, to adequately administer these complex rules. One hearing participant, for example, cited the National Academy of Social Insurance finding that 75 percent of all recipients earning between $600 and $1,000 a month were charged with overpayments in the 12 months prior to September 1994.[8]

The director of services for the Northwest AIDS Foundations wrote that

> *The complicated payment structure of the Social Security Administration (SSA) must be changed. Many of our clients who return to work receive overpayments from the SSA and must either return the money or attempt to have the overpayments waived. This is a costly system that discourages many individuals from considering returning to work.* (Brian Giddens, Seattle, Washington)

An obviously distraught individual wrote,

> *The real tragedy is that these stupid and too often serious errors, this gross negligence on the part of SSA, has cost me (at times) a decent place to live and needed medical and dental care—I may lose my back teeth as a direct result of this plus the current bungling of Medicare. . . . Now, after 20 years of permanent disability and all I've been through, SSA is trying to prove that I've "medically*

[8] NCD found this citation to be correct. It is on page 159 of *Balancing Security and Opportunity: The Challenge of Disability Income Policy* (Washington, DC: National Academy of Social Insurance, 1996). The data come from SSA's Office of Supplemental Security Income and they show that 60 percent of all individuals earning more than $65 per month in that period (95,600 individuals) were charged with overpayments.

improved." I've been harassed, harangued, badgered, and adversely affected by what I, and a good attorney, would perceive as "intentional infliction of emotional distress"; my medicals will demonstrate posttraumatic stress syndrome, for sure! I wouldn't wish what I've been through with SSA on my worst enemy. Too many of these bureaucrats have set themselves up as demigods! (Sten Nilsson, New York)

A benefits advocate said,

The use of all work incentive programs must become less bureaucratic and bogged down in voluminous regulations. People are afraid to use these programs because they are so hard to use and understand. People are also scared to death of getting hit with a huge overpayment because of the Social Security practice of continuing to pay benefits after they are scheduled to discontinue and other slow bookkeeping practices. By the time people get overpayment notices, these overpayments have become unmanageable. (Unidentified, Topeka, Kansas)

The following action proposals to the 105th Congress and beyond address these fears and barriers.

Action Proposal 1: Provide Medical Coverage for Workers With Disabilities

Congress should require States to provide Medicaid coverage (under 1619b) to all SSI recipients and DI beneficiaries who, as individuals, have earnings below their State or individual thresholds. Medicaid should cover long-term services such as personal assistance, assistive technology, housing modification, and medical supplies. For DI beneficiaries covered by Medicare and those who can access health insurance through their employers, Medicaid should provide wrap-around

coverage for those services and costs not covered by Medicare or the employer's insurance.

Congress should establish a Medicare buy-in program that would allow DI beneficiaries whose individual earnings exceed $15,000 per year to purchase Medicare coverage on a sliding scale tied to earnings.

Congress should require States to establish a Medicaid buy-in program (called 1619c) for all SSI recipients and DI beneficiaries whose earnings exceed the State or individual threshold. The buy-in should be based on a sliding scale tied to an individual's earnings. The buy-in should be less costly for those who receive wrap-around coverage and need only to supplement Medicare or their employers' insurance.

Loss of Medicaid or lack of access to adequate health insurance is the number one concern of people with disabilities who want to work. Consumers and advocates across the country said that they would work if they had access to Medicaid that covered not only their immediate needs but also such long-term services as personal assistance, assistive technology, housing modification, and medical supplies. Covered services should specifically include assistive services and technology needed by people with visual impairments. (See the testimony from Kansas under Action Proposal 2 for more on this point.) Medicaid wrap-around policies should be available for those who have Medicare or who can access insurance through their employers. These wrap-around policies would cover those costs normally covered under Medicaid but not under Medicare or the employer's insurance. If people with disabilities cannot get this coverage, more than one person said, then they actually fear for their lives.

Action Proposal 2: Replace the DI "Income Cliff" With Gradual Benefit Reductions

Congress should establish similar rules for SSI and DI that would give full benefits to those earning less than $500 per month and would reduce cash benefits by $50 for each $100 of earnings above that level—with adjustments in benefit levels made quarterly instead of monthly. This provision would replace the current trial work period provision.

Individuals eligible for the $1,000 blind SGA (substantial gainful activity) amount could choose to remain under current rules or switch to the $500 earned-income exclusion and $50/$100 reduction. For those receiving additional DI amounts for dependent children, the $50/$100 reduction would apply to the total amount of DI received, including the dependent allowance.

The $500-per-month earnings level should be adjusted annually to reflect changes in the Consumer Price Index (CPI).

Although many believe that this $500-per-month earnings level bears no real relation to significant earnings capacity, most accept it as an arbitrary starting point for a rationally determined reduction in support to individuals with disabilities who are able to earn significant incomes. A few hearing participants railed against the $500 level; but from their testimony it was apparent that they were thinking of it as an all-or-nothing trigger (as is currently the case with DI after the trial work period) rather than as an earned-income exclusion in determining a gradual benefit reduction.

Figure 1 shows the results of a WorkWORLD analysis[9] of the effects of current policies compared with the effects of the first two action proposals on the net income[10] of an individual receiving the average DI benefit of $704 per month.[11]

The graph plots gross earnings, from $0 to $33,000 a year in $3,000 increments, versus net income. At each $3,000 increment, a dark bar shows the DI beneficiary's net income under current policies; and a lighter bar shows the individual's net income under the action proposals.

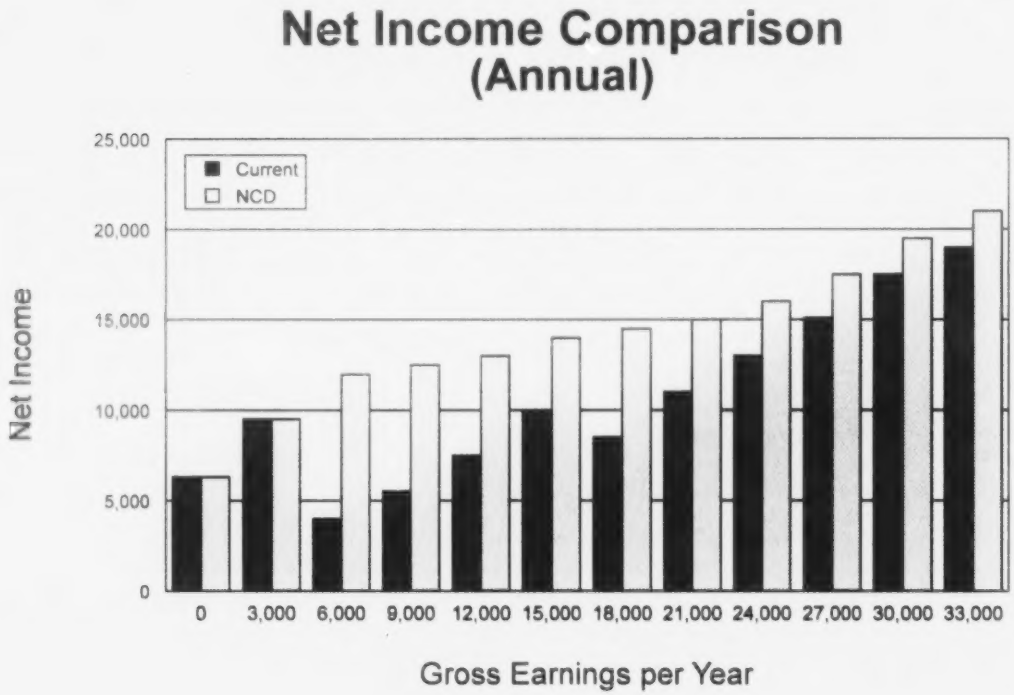

Figure 1 This graph shows the effect of the net income of a person who receives $704 a month in Disability Income benefits if he or she goes to work under current policies and under the NCD action proposals for Medicaid/Medicare coverage and gradual benefit reductions.

[9] The results are shown in graphic format. This report also fully describes the significant results so that those readers who have access only to the text will have all of the relevant information.

[10] "Net income" in this simple case is an individual's earnings, plus DI benefits, minus taxes paid and buy-in amounts. In a later look at the work expense proposal, WorkWORLD will also subtract work expenses.

[11] Tables showing the numbers behind all the WorkWORLD graphs are available from ESI. E-mail David Ruth at druth@vcu.edu with fax number or call 804-828-1992.

The dark bars show that at $0 and at $3,000 per year, the current policies and the proposed policies yield the same net income (a little less than $10,000 net income per year at $3,000 per year of earnings). At $6,000 per year of earnings, however, an individual under current policies who has used up the trial work period would face a net income drop of $5,700 to $3,800 a year. Under the NCD proposals, the individual's income would rise to $12,200 per year.

Both the dark and the light bars show that at earnings between $6,000 and $15,000 per year, an individual would see net income rise under both the current policies and the proposed policies. At earnings of $15,000 per year, however, the individual laboring under current policies would realize $4,500 per year less in net income than the individual working under the proposed policies.

The black bars also show that between $15,000 and $18,000 in earnings, there is another income cliff or drop in net income under current policies. This smaller cliff is caused by the current Medicare buy-in provision that allows an individual to purchase Medicare at $332 per month. The proposed buy-in, on the other hand, keeps the net income curve moving upward because the cost of purchasing Medicare coverage would be on a sliding scale instead of the current all-or-nothing basis.

Caveats Concerning Individuals Who Are Blind

Some individuals with visual impairments strongly suggested at the hearings that earnings reductions should begin at a DI beneficiary's current SGA amount. SGA for blind DI beneficiaries is $1,000 per month versus $500 per month for those with other disabilities. An individual from Kansas gave the following rationale for the SGA difference:

> *The idea that all disabled people who receive SSDI should have the same substantial gainful activity level assumes that the benefits and covered costs of being disabled, or costs of attempting to live independently as a disabled person, are the same or enjoy the same third party coverage, across the board and across all disability groups. This simply is not true.*

> *. . . Readers for blind people allowing them to handle their business independently; sighted guide services, if needed to travel in unfamiliar areas; shopping assistance; environmental descriptive services; etc., however, are not covered for persons who are blind under Title XIX or any other source.* (Michael Byington, Topeka, Kansas)

NCD believes that full funding of assistive services and technologies should be provided under Action Proposal 1 for Medicaid and Medicare coverage, including services and equipment that would help people with visual impairments. NCD also believes that these services can be covered under the tax proposals described under Action Proposal 4.

NCD fully supports a "hold harmless" provision that would allow people with visual impairments to choose whether to receive their benefits under the current DI rules or the proposed gradual reduction of benefits. The following analysis of these options with WorkWORLD software, depicted in Figure 2, demonstrates that the current rules would be preferable for individuals with visual impairments in only a very narrow range of circumstances.

Figure 2 shows what an individual's net income would be when the individual is unemployed and when he or she has increasing earnings levels under current rules compared with what it would be under the action proposals in this report. The analysis is for a DI beneficiary receiving the average DI benefit of $704 per month who qualifies for the blind SGA amount of $1,000 per month.

Figure 2 shows that blind DI beneficiaries who earn between $6,000 and $12,000 a year would be somewhat better off under the current rules. Those earning $8,600, for example, would have a net income of $14,070 under current rules and $12,870 under the proposed changes; and if they have no prospect of earning $12,000 per year, they would be better off under the current rules. If, however, they have a chance to earn $12,000 or more, they would be much better off with the proposed rules. Blind DI beneficiaries earning $12,000, for example, would have net incomes of $8,202 under current rules, but they would have $13,605 under this action proposal.

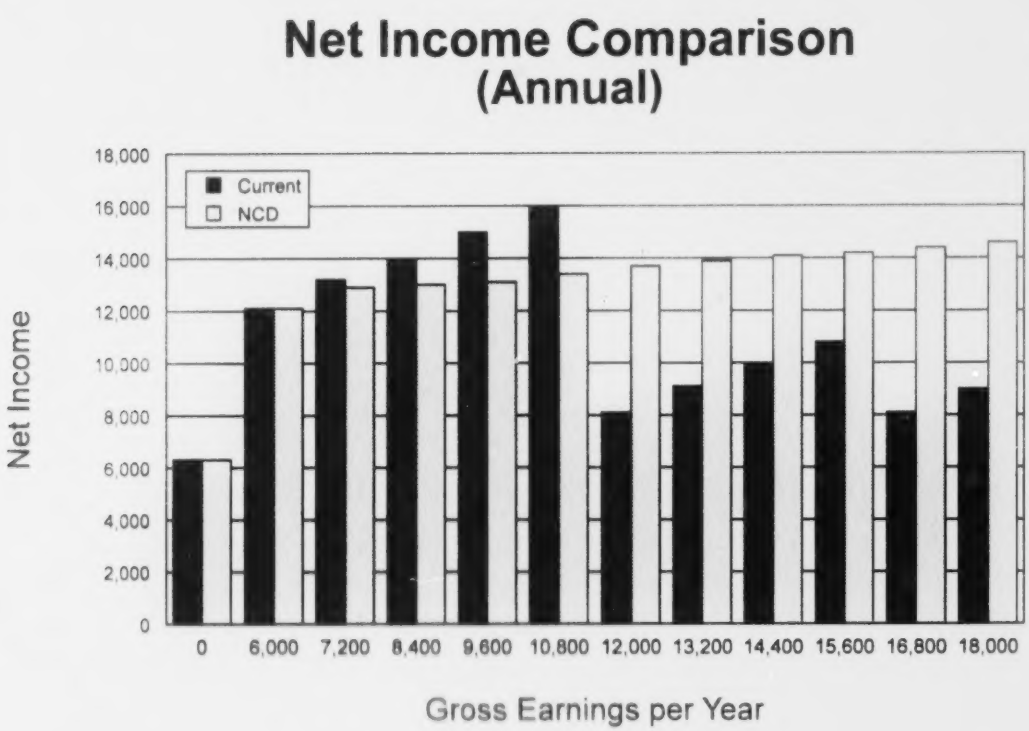

Figure 2 This graph shows that, among blind persons, only those who earn between $6,000 and $12,000 a year are better off with current policies. (This analysis assumes that the person has no work expenses.)

SSA Administrative Cost Savings

Another aspect of Action Proposal 2 (Replace the DI "Income Cliff" With Gradual Benefit Reductions) that deserves more than passing comment is the fact that it would radically decrease both SSA's administrative expenses and the incidence of over- and underpayments. First, this proposal would reduce the administrative burden by having both the DI and SSI programs ignore earnings of less than $500 per month, eliminating the need to make earnings adjustments for more than 45 percent of SSI recipients. Second, it would require adjustments only for large changes in income, because the adjustments would be made only for changes in earnings of $100 per month or more. Third, making changes quarterly instead of monthly would require check adjustments only 4 times a year instead of 12. Currently, very small changes in

earnings (changes that can occur, for example, because there are five paychecks in a month instead of four or because an employer asks a worker to work a few hours of overtime in a given month) require SSA to alter the SSI benefit amount. The relatively larger increments required for benefit changes under the proposal would mean that SSA would not have to make monthly adjustments for those workers who are in relatively stable situations but who happen to be paid weekly or to have small overtime opportunities.

Dependent Benefits

Before holding these hearings, NCD had not realized how important the benefits received by dependents of DI beneficiaries are in the employment equation. However, many individuals indicated that a critical element in their employment decision was the fact that if they went to work they would lose not only their own benefits, but also the benefits for their dependent children. The recommendation to gradually reduce workers' benefits commensurate with earnings was good, they said; but if their children's benefits were lost, then they would be in desperate straits.

A number of people recommended that dependent benefits not be affected by employment. These benefits, they said, should depend only on eligibility; and eligibility should not be affected by work activity. Many others, however, felt that although dependent benefits were important, they should decrease with increased earnings just as primary benefits would under this action proposal. Therefore, NCD proposes that dependent benefits be lumped in with primary benefits when determining the $50/$100 decrease in benefits due to earnings.

Index the Earned-Income Exclusion

Finally, NCD recommends that the earned-income exclusion amount, $500 per month, be indexed to the CPI. This would acknowledge that people with disabilities are working within the same economic system, with the same inflationary realities, that all Americans have to deal with. It also would gradually bring the $500 threshold closer to the current $1,000 SGA for blind individuals and increasingly narrow the number of individuals who would be forced to choose between current and proposed rules.

Action Proposal 3: Ensure That People Do Not Lose Eligibility Because They Work

> Individuals whose SSI or DI cash benefits have stopped because of their earnings—but who have not medically recovered from their disability—should remain eligible for future benefits in the event that their earning ability declines.
>
> Congress should ensure that CDRs are carried out on schedule (every 3 or 7 years, depending on the disability) and are not triggered by work activity.

Enacting this proposal would drastically reduce one of the major fears discouraging those who could earn significant amounts of money (and thus pay significant taxes) from doing so. Making continued eligibility contingent only on medical recovery, not earnings, would reduce individuals' concerns that they might not be able to work in the future. Under the current system, if they lose their job after losing eligibility for SSI or DI benefits because they had been earning, they would be without earnings and benefits while again going through the grueling application process. This fear is especially strong among those who have episodic disabilities, such as mental illness, and degenerative disabilities, such as multiple sclerosis and arthritis.

The *New York Times* recently published the story of a Manhattan physician who had lost his DI eligibility because he "worked 3 months too long."[12] Dr. Luis Kaplan had lost one leg to cancer in 1990. Although qualified for DI and Medicare benefits, he was able to resume his practice after rehabilitation by getting around on crutches. Unfortunately, after 4 years and 3 months of working, Dr. Kaplan found that arthritis in his arms prevented him from continuing. His DI benefits of $1,235 per month were restarted and continued for the next 2 years, until SSA realized that Dr. Kaplan had worked 3 months past his extended period of eligibility. SSA informed Dr. Kaplan that he no longer had Medicare, that he would no longer receive his monthly DI check, and that he owed SSA $24,813.90 in benefits he had mistakenly received. Dr.

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[12] Esther B. Fein. "What Is Disabled? He Thought He Knew: Doctor Finds That Working Too Long Costs Him Social Security Payments." *New York Times*. Tuesday, August 12, 1997 (Late Edition, Final).

Kaplan told the reporter that he could not believe that a man with arthritis and an amputated leg would lose his eligibility because he tried too long to keep working.

Enacting the second part of this action proposal would mean that SSA would carry out CDRs in accordance with the schedule appropriate for the disability type (every 3 years for disabilities where medical improvement is possible and every 7 years when medical improvement is not expected). SSA should not schedule additional CDRs simply because an individual goes to work. Removing the earnings trigger for CDRs would mean that SSA could, as one hearing participant suggested, send new workers a letter of congratulations rather than a warning that they could lose their benefits.

Action Proposal 4: Compensate for Disability-Related Work Expenses

Congress should establish a disability work expense (DWE) tax credit that would reimburse 75 percent of an individual's disability-related work expenses. The reimbursement could not exceed the individual's gross earnings and would be capped at expenses of $15,000 per year. The credit would begin phasing out at earnings of $50,000 per year and be completely phased out at $75,000.

This tax credit would be refundable, meaning that those who owe no taxes could still receive it as a refund. The credit could be received either in installments in each paycheck—if an individual files the appropriate tax form with the employer—or in quarterly or yearly refunds from the Internal Revenue Service (IRS).

The current tax deduction for impairment-related work expenses should be retained to cover expenses not reimbursed by the above credit. Both the credit and the deduction should cover expenses related to preparing for and traveling to and from work, as well as expenses incurred at work.

The DWE tax credit would replace the current impairment-related work expense (IRWE) work incentive with a straightforward 75 percent reimbursement for disability-related work expenses. The current IRWE not only is complex, but also has different effects in the two Social Security disability programs. In both programs, the work expense amount is subtracted from gross earnings before determining the effect of earnings on benefits. In the DI program, the effect is to keep the whole DI check coming if gross earnings minus work expenses are less than $500 per month. In the SSI program, the effect varies with the circumstances. Both the rate of reimbursement and the total amount of reimbursement depend on the amounts of earned and unearned income a person has, as well as the work expense amount.

Under the current IRWE rules, for example, an SSI recipient earning $65 per month with $100 in IRWEs gets no reimbursement. A recipient earning $300 per month would get $50 as an IRWE reimbursement. That same person, however, would get only $11 in IRWE reimbursement if he or she happened to be a dual SSI-DI beneficiary getting $425 per month of DI. In fact, that $11 would be the whole SSI check. (These calculations were made with WorkWORLD software. The typical SSI recipient could hardly be expected to be able to predict such effects without the benefit of the software.)

In contrast, the DWE tax refund would be very predictable. It would be 75 percent of the disability-related work expense or the earnings amount, whichever is lower. In the above example, then, the person earning $65 per month with $100 in work expenses (about the cost of monthly paratransit services in many places) would get a DWE tax refund of $65 per month. The person earning $300 per month would get a tax refund of $75 per month, whether he or she was an SSI recipient only or a dual SSI-DI beneficiary.

Workers could choose how they receive the work expense reimbursement. They could file a form with their employer estimating the cost of the work expense, and the employer would subtract the refund from the taxes to be deducted and add the rest of the reimbursement, if any, to the paycheck. Alternatively, they could receive their refund directly from IRS, either in a lump sum at the end of the year or in quarterly payments if they file quarterly estimated taxes. (NCD believes that workers who do not want to self-disclose to employers must be allowed the option

of filing and receiving quarterly refunds, and this alternative must be explicitly provided in the tax credit legislation.)

- Although not everyone who testified concerning the DWE tax credit proposal agreed that bringing IRS into the picture was a good idea, NCD agrees with those who pointed out that dealing with IRS is "normalizing," since all working people must do so. (Even low-income earners must file with IRS if they want to receive the earned income tax credit, another refundable tax credit.) Dealing with IRS also is less demeaning most of the time, since it is the worker who would estimate and claim the work expense, not a claims representative. Individuals would have more control of the process because they could file an estimate of their expenses ahead of time and then file an amendment if the expenses changed significantly. Finally, low-cost, expert tax advice is readily available, while expert advice on SSI and DI claims can be much harder to find.

Perhaps the most important reason NCD is proposing a DWE tax credit in lieu of the IRWE incentive is that in many circumstances, the tax credit removes a financial barrier to employment that is inflicted by IRWE. A WorkWORLD analysis, for example, shows the effects of an IRWE versus a DWE tax credit for a dual SSI-DI beneficiary who has high work expenses. Figure 3 shows what happens to an SSI recipient who receives $450 in DI each month and who has $400 per month in disability-related work expenses.[13] The graph compares the effects of (1) current policies, including using IRWE to cover the $400 in work expenses; (2) the NCD proposals, but retaining IRWE; and (3) the NCD proposals with the DWE tax credit proposal.

Figure 3 shows that at earnings of $3,000 per year, the worker would see a drop in net income of about $1,800 under both the current policy and the NCD-IRWE option. With the DWE tax credit, however, the NCD proposals result in an increase in net income of $1,000.

Both under current policies and under an NCD-IRWE alternative, individuals earning $6,000 per year would have only about $1,000 more in net income than when unemployed. With the NCD-DWE proposal, however, net income would go up about $4,500. At each higher

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[13] Such a person might be someone with a traumatic brain injury (TBI) who was injured after a few years of working and who now needs 10 hours per month of ongoing job-coaching services to maintain employment. In many States, funding for such ongoing services are not available to people with TBI.

increment of earnings, individuals do better with the DWE tax credit proposal than if NCD retained IRWE as the method of compensating for work expenses.

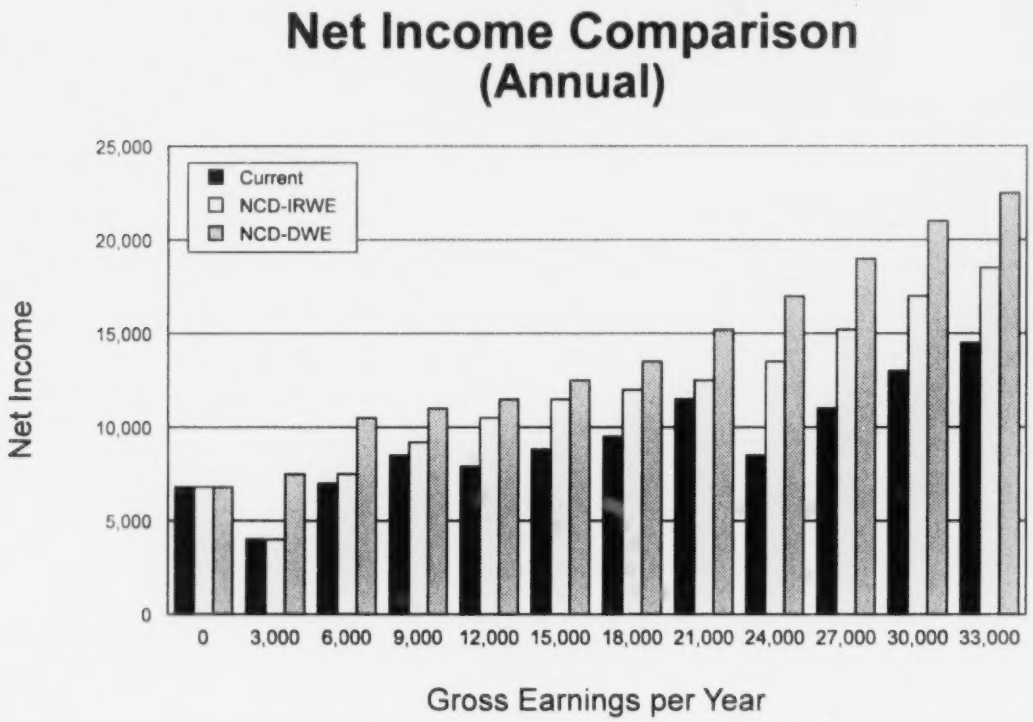

Figure 3 This graph compares net income under current policies and impairment-related work expense and disability work expense tax credits. (The person is a Social Security Income recipient who also receives $450 per month in Disability Income and has disability-related work expenses of $400 a month when employed.)

Action Proposal 5: Remove Marriage Penalties

Congress should ensure that Social Security benefits are based on individual earnings and income. SSA should not penalize beneficiaries for being married or for being disabled adult children of disabled, retired, or deceased beneficiaries.

Some of the most troubling and bizarre stories told during the hearings involved what beneficiaries and recipients call "the marriage penalty." (See examples of their testimony in the introduction to this section.) People who can barely survive on their current benefits find that if they marry, and often if they gain employment after they marry, they risk their very survival. The simple remedy that many suggested—which NCD agrees with—is that SSA treat individuals as individuals and discontinue the complicated provisions that treat the income of spouses as income of beneficiaries and cut off disabled adult children who marry.

Action Proposal 6: Waive No-Fault Overpayments

> Congress should instruct SSA to collect SSI or DI overpayments only when an individual fails to report a change in income, intentionally misrepresents income or earnings information, or otherwise engages in fraud. Overpayment waivers should be granted quickly and routinely when SSA has made overpayments and the SSI recipient or DI beneficiary is not at fault.

A large number of individuals who testified at NCD hearings told their "overpayment" stories. These stories are no doubt widely circulated among the disability community, and they serve to discourage even the most ambitious from going to work and taking the overpayment risk. Many of the stories were of overpayments that resulted from SSA mistakes. Enacting this proposal would put the responsibility for those mistakes where it belongs.

NCD also believes that a number of the other action proposals will result in a drastic reduction in overpayments and overpayment mistakes. Raising the earned-income exclusion for SSI recipients from $65 to $500, for example, would eliminate the need to change the benefit levels for nearly half of those SSI recipients who are currently working.

Raising the earnings increment that results in benefit reductions from $1 to $100 should also reduce the overpayment problem, because the monthly changes due to weekly pay periods and small overtime amounts should be eliminated. Making changes in income reportable

quarterly instead of monthly should also result in a large reduction in the number of overpayment mistakes that are made.

Probably most important of the other action proposals that affect overpayments is the elimination of the complicated and difficult-to-administer trial work period (TWP) for DI beneficiaries, along with its all-or-nothing provisions and its 5-year rolling time period. (TWP would be eliminated if Action Proposal 2 were enacted. That is the proposal to replace the DI income cliff with an immediate $50/$100 reduction of cash benefits.) Many of those who testified had learned that they owed SSA thousands of dollars because their TWP had been incorrectly calculated, and the error was discovered long after the fact.

Finally, ensuring that individuals who have not medically recovered retain their eligibility, thus eliminating DI's extended period of eligibility, would eliminate cases such as that of Dr. Luis Kaplan, the physician who owed almost $25,000 because SSA did not realize for 2 years that he had worked 3 months past his deadline.

This action proposal deals with the residual overpayments that are still made. Individuals should not have to reimburse overpayments unless the individuals are at fault. Individuals would still be responsible for reporting any income changes in a timely fashion, and they would have to pay back overpayments that result from their own failures to keep SSA correctly informed of their earnings and income.

Action Proposal 7: Raise Resource Limits

> Congress should raise the resource limits for SSI eligibility from $2,000 to $5,000 and exempt Super IRAs, qualified plans, and medical savings accounts from this resource limitation. These plans allow tax-favored savings for education, medical emergencies, or retirement and should not affect SSI eligibility.

Even the proposed limit of $5,000 was thought too low by many who testified. They said that such limits keep them in poverty because the limits prevent them from saving in order to move, to start a business, or to have money for emergencies. NCD agrees that even the $5,000

resource limits prevent individuals from saving for business ventures and many emergencies, but the Plan for Achieving Self-Support (PASS) proposal (below) should adequately deal with the need for business startup funds. Action Proposal 1 would provide that resource limits not be imposed for Medicaid and Medicare coverage and buy-ins, the number one concern of those who testified.

Action Proposal 8: Increase SSA Accountability to Stakeholders

> Congress should establish an oversight group composed of stakeholders outside of SSA, including employers, service providers, and at least 51 percent consumers (beneficiaries, recipients, and a limited number of family members). This group would be federally funded, independent of SSA, and authorized by Congress to recommend employment-related regulations and to monitor their implementation.

This proposal addresses the concerns of all those who testified that they have found SSA to be unresponsive to their needs. This oversight group would not replace the current appeal system for individual complaints; rather, it would deal with the larger issues of regulatory and policy matters. This group, for example, would deal with the current problems with the PASS program that were raised so frequently during the hearings.

Barrier: People With Disabilities Cannot Choose Their Own Vocational Rehabilitation Program

When individuals apply for SSI or DI benefits, they are required first to prove that their disabilities prevent them from earning more than $500 per month. They then must wait a long time for services to help them become employed, and most never receive an offer for such services. Those who are offered vocational services have few choices in the services they can access and have little information upon which to base their choices.

An individual from Alaska submitted as testimony a May 1997 paper by George Washington University's Allen Jensen summarizing the efforts of a number of States to institute work incentive reforms.[14] One of the two most common reform measures was to provide referrals to vocational services as early as possible in the disability application process. (The other most common measure was to ensure medical insurance coverage.) An individual at the Seattle hearing cited a report by the General Accounting Office (GAO) saying that an early return to work was crucial to employment success. Waiting months for a vocational referral, he said, was ridiculous.

Several participants at the Albuquerque hearing, especially those from the Navajo and Hopi tribes, spoke about the limited number of services available in their communities. Service providers, one said, can come from as far away as 200 miles. The participants favored the provision of vouchers, believing that consumer choice and vouchers would ensure that more services would become available in their communities by encouraging local community members and agencies to become involved in service provision. The participants preferred a system of local service providers to reliance on professionals from larger communities. Essentially the same message about service availability, and the possibility that vouchers could improve that availability, came from an inner-city resident of Baltimore. Finally, a number of consumers at the Minnesota hearings emphasized their need for choice among service providers. A ticket or voucher system could give them that choice.

The head of the disability supports unit of a State Department of Human Services said,

Lack of choice in providers and employment service is a second barrier to employment. [Fear of losing benefits and of having overpayments was the first barrier.] Consumers receiving inadequate service have no recourse for the selection of another provider unless they are willing and able to purchase the

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[14] Allen Jensen's paper, "Summaries of State Profiles of State's Initiatives to Develop Projects to Reduce Work Disincentives for Persons With Disabilities," was written under contract with SSA.

services themselves. Funding should be opened up for competition to allow consumers to purchase the supports needed from quality, appropriate providers.

Some Houston conference participants and a few hearing participants said that there are some individuals whose disabilities will always prevent them from earning more than $500 per month. They warned that any reforms should not jeopardize the supports needed by such individuals. Other participants, while not disputing that those who cannot work should be protected from harm, commented that there are many more individuals with disabilities who could earn a significant amount and be much more (if not completely) financially self-sufficient. They could do so if the fears identified above were reduced and if they had access to and information to make choices about training programs, employment counseling, adaptive equipment and transportation, and, in many cases, resources needed to start their own businesses. The action proposals for the DWE tax credit would help individuals pay for employment services, but NCD has heard from the disability community that other remedies also are needed.

A few hearing participants extolled SSA's PASS for allowing the purchase of services and equipment, transportation, and business investments that enabled them to become more self-sufficient. Most, however, focused either on difficulties with PASS or on recent changes in SSA's administration of the program. A few examples of the testimony follow:

These plans are arcane, difficult to use, and [it is hard to] find Social Security personnel who know what to do with them, and [the plans] only work for people saving for large capital investments. (Nancy Becker Kennedy, Los Angeles California)

In March of '94, I was approved for a PASS for school and to start my own at-home business. Several months ago I got a letter in the mail saying that I owe them $1,800 in back pay. I have asked for an appeal. I don't get that kind of money to be deducted from my Social Security. I can barely pay my living quarters. . . . I applied for another PASS to help me get the equipment to help me

start the home business. I was turned down. I lost my car which I got for part of the PASS to help me get the business started and to get back and forth to school. . . . I used to be self-supported. I would like to be like that again. (Aleph Wright, address unknown)

I work with hundreds of claimants each year. The PASS rules were changed subversively without review of Congress and without input from people with disabilities. The new rules seem to provide disincentives rather than incentives for people to try to return to work. My experience, since the regulations have been changed, is that no clients I have worked with have had a PASS approved. (Richard St. Denis, attorney with the Center for Disabilities, Boulder, Colorado)

The PASS program as recreated unilaterally by SSA will work for no one. . . . The SSA changes that [we] find most outrageous are as follows:
—PASS use only for entry-level jobs (which means no one with a severe disability can ever get off the dole)
—No using PASS money for payments (long delays in even starting to work)
—Cannot save for van unless you can drive it yourself (just plain idiotic and probably a policy violation of 504 and the ADA)
—Unannounced moratoriums on PASS plans, leaving many broke and bankrupt as they were in the middle of a plan." (Julie Reiskin, executive director of the Colorado Cross Disability Coalition)

PASS is the only useful tool and must be fixed immediately. Get rid of restriction to entry-level jobs. In the GAO study, people said they purchased cars, computers, and small businesses; and SSA took these three things out of PASS plans. These things work. The excitement of PASS plans was not engendered by any other system. VR has not been effective in helping people start small businesses either

and will not help with cars or computers. PASS regulations need to be revised to reflect the program before the [recent] revisions. (Anonymous)

Following are the action proposals to the 105th Congress and beyond to address these needs.

Action Proposal 9: Provide Immediate Access to Employment Counseling

Congress should designate a portion of the savings to the Social Security Trust Fund to establish grant-funded employment counseling services nationwide and ensure that all SSI and DI applicants are immediately referred to such services when they make initial application to SSA for disability benefits.

Employment counselors would (1) explain to applicants how to use the work incentives associated with SSI, DI, and other benefits; (2) inform applicants of the vocational training and other supports available to them through vocational rehabilitation (VR) agencies and other organizations; and (3) help applicants navigate through the bureaucratic maze so that they can make full use of the work incentives and employment services.

Some participants at the Houston conference and a few of those who testified during the hearings thought that the employment counselors should be SSA employees housed at SSA field offices. However, most of those who addressed this issue stressed that such counselors should be part of organizations that have expertise in the employment area and that they should be independent of the local SSA offices.

Action Proposal 10: Increase Access to and Choice Among Service Providers by Instituting a "Ticket" or "Voucher" Program

Congress should create a "ticket" or "voucher" program that enables most SSI recipients and DI beneficiaries to select and buy services leading to employment.

Individuals should be allowed to choose from a wide array of service providers, including educational institutions, training facilities, job-coaching services, and assistive technology. The tickets should be financed from the savings to taxpayers that result from individuals going to work, thus leaving the benefit rolls. The tickets should provide sufficient reward to service providers to be an incentive for them to participate in the program. Advance payments should be made for milestones such as the completion of a training program, job placement, and a period of time on the job. Services covered by any voucher proposal should include the purchase of technology or equipment, tuition for college or vocational school, or other training and support needed to work. SSI recipients and DI beneficiaries should control the allocation of those vouchers.

The director of a head injury support group in Mississippi said that providers need financial incentives to train and find jobs for people with head injuries. She agreed with the concept that providers should be paid for successes. The Social Security coordinator for a State VR agency said that any ticket or voucher should be available for the State VR agencies as well as private providers. This action proposal would not limit payments to private providers.

Although there was much consumer support for the ticket or voucher idea, that support was neither unequivocal nor universal. One consumer from Minnesota, for example, expressed dissatisfaction with VR services and said, "I wish you would give me the money you're spending on me so that I could decide what I want to do." Another suggested that "giving money to private providers is just giving money to people who are not disabled" and should not be a priority. A California consumer said,

I'm afraid that I must also take issue with the "voucher" system under which people can choose from a number of public and private agencies. Although this idea sounds good on its face, it will result in a two-tiered system, in which the least disabled, best educated, and most effectively advocated people will be

creamed by the private facilities and the most disabled and hardest to rehabilitate will be ghettoized with the state VR Agency. (Roger Petersen, member, Board of Directors, California Council of the Blind)

Some providers of services also had their doubts. The director of rehabilitation services for a Minnesota agency, for example, said she had the following concerns:

a) When an agency is being asked to accept a difficult-to-place person, it would be even more reluctant to accept this person when chances are payment wouldn't be forthcoming;
b) While, happily, the beneficiary may choose to go on to school or seek other training after the initial rehabilitation training, it would delay payment to the agency providing the initial training. Most agencies could not afford to wait for payment; and
c) After successful rehabilitation, the beneficiary may either refuse to work or cannot work due to a circumstance not related to the initial rehabilitation. Does the agency providing the service still get paid? Consumer choice is important and necessary, but it shouldn't be at the expense of the agency providing the training."

Despite these caveats and concerns, NCD believes that the provision of more employment services and more choice among services, especially when the services can be tied to success and funded from savings to the system, is very important to consumers who want and need employment services. Under the current system, State VR agencies are reimbursed by SSA for "successfully rehabilitating" only about 6,000 people per year of the millions of individuals on the SSI and DI rolls; and the majority of those successes are actually placements into sheltered employment or into unpaid homemaker positions.[15]

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[15] More detailed statistics are available in tables on pages 102 and 106 of *Balancing Security and Opportunity* (National Academy of Social Insurance, 1996).

The concern that private service providers might cream off the "the least disabled, best educated, and most effectively advocated people" and not take the risk of working with people who have severe disabilities is offset by other testimony and research evidence, NCD believes. Service providers have found that motivation to work, not severity of disability, is the most important factor in predicting job placement success.[16] It is much easier to place a highly motivated individual with severe cerebral palsy than an individual with lower back pain who wants to retire on disability. Creaming highly motivated individuals is a good place to start.

NCD recognizes that some service providers may not choose to take the risks outlined in the testimony by the Minnesota director of rehabilitation services. NCD believes, though, that a voucher program offers fewer risks and more worthwhile rewards for success than alternative programs that have been proposed or are currently being implemented. SSA, for example, is currently implementing its Alternate Provider Program, in which private providers of employment services can be reimbursed for the costs of successfully helping individuals that the State VR system chooses not to serve. That program may not sufficiently reward providers, however, because it pays them only enough to cover the costs of their successes. The costs of serving those individuals who do not find and maintain employment must somehow be borne by the provider. The possible rewards, many providers say, do not compensate for the risks.

NCD recommends that a payment system be devised that rewards providers sufficiently that they will take risks by serving individuals with severe disabilities who want to work. Such a payment system, NCD believes, would overcome the resistance to the ticket proposal that surfaced in some of the testimony. Even if some agencies do not avail themselves of this funding to the extent that some advocates would hope, NCD believes that the chance to increase service availability and choice is worth the risk.

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[16] See, for example, a number of the research articles in *Life Beyond the Classroom: Transition Strategies for Young People With Disabilities*, edited by P. Wehman (Baltimore, MD: Paul H. Brookes Publishing Co., 1996).

Action Proposal 11: Provide Access to Information About Providers

> Congress should establish, with enabling legislation if necessary, a grant program that would fund independent evaluations of rehabilitation providers around the country. The evaluations should be based primarily on outcome measures such as number and type of placements, wages, types of disabilities served, and consumer response, thereby providing users with consumer-based information to aid in their decision making. The funding should also provide for the local dissemination of the information.

One advocate from a California Independent Living Resource Center agreed that

> *Consumer choice is a key element . . . however, informed choice is not a list of providers, but a report comparing providers on items such as services offered, languages spoken, percentage of participants completing a program, placement rates and wage level, etc.*

On the other hand, another California consumer-advocate warned against establishing yet another accreditation program, especially a program that on the local level might make one of a number of rival agencies (the one winning the grant) the judge of quality in that area. Taking this warning into account, NCD recommends that two types of information be gathered: (1) purely factual outcome data and (2) aggregated survey responses of SSI recipients and DI beneficiaries who use vouchers. The information would not duplicate the kinds of process and documentation data collected through standard accreditation evaluation techniques such as document reviews and staff interviews. The disseminated information would truly be consumer based.

Action Proposal 12: Provide Access to Investment Funding

> The Plan for Achieving Self-Support (PASS)—or a PASS-like program—which allows consumers to invest in training, equipment, or other assets needed for employment, should be retained, simplified, and made available to both SSI recipients and DI beneficiaries.

A redesigned program should restore at least the original flexibility of PASS, lessen the degree of micromanagement by SSA, and simplify documentation procedures.

Hearing participants commented that the tax credit for work-related expenses was not enough. People need up-front investment money to get assistive technology, training, and equipment to start small businesses. However, there were few positive suggestions about how the PASS program should be redesigned to be useful to more than a small minority of SSI recipients and DI beneficiaries, other than recommending that the recent changes in the PASS program be rolled back. NCD recommends, therefore, that the oversight group proposed in Action Proposal 8 develop guidelines for revamping PASS.

Action Proposal 13: Eliminate the Scholarship Penalty

> Congress should direct SSA to exclude all scholarship and fellowship income in determining both initial eligibility for SSI and cash benefit amounts for SSI and DI.

One hearing participant told of having to turn down a scholarship and forgo an educational opportunity in order to remain eligible for SSI and Medicaid coverage. A number of advocates also spoke of the absurdity of penalizing people who have earned opportunities for educational advancement. Currently, a scholarship covering $500 per month in living expenses would result in a loss of both SSI and Medicaid because such money is treated as unearned income and would not therefore qualify an individual for 1619a benefits above the SGA level. A

lesser scholarship would reduce the SSI check dollar for dollar. SSI recipients should be encouraged, not discouraged, from seeking scholarships and furthering their education. Doing away with this penalty seems to be, in the words of one participant, a "no-brainer."

Barrier: People With Disabilities Lack Employment Opportunities

People with disabilities face a daunting challenge when they try to find employment. They must not only overcome the limitations imposed by their disabilities, but also compete with recent high school and college graduates, the victims of industry downsizing and relocations, and all the welfare recipients who now must go to work.

Furthermore, many employers are reluctant to hire a person with a disability. Employers fear increased health insurance costs, the need to provide reasonable but possibly expensive accommodations, and the perceived need to deal with adverse reactions by customers, coworkers, and supervisors who might be uncomfortable around people with disabilities.

Employers' first fear, that they could face increased health insurance costs, would be alleviated by NCD's proposal for a Medicaid buy-in with wrap-around coverage. The following testimony and proposals address the other fears and competitive realities.

Two California consumers said,

> *Employers need to be encouraged to hire both mentally and physically disabled people, accommodate them, and pay them a living wage, with the support and encouragement of the Government.* (Ana Harris)

> *I believe that without active advocacy and incentives to encourage employers to hire people like me, opportunities will be slim.* (Bertha E. Johnson)

Another consumer said,

Small employers should get federal funds to accommodate needs of disabled workers. This should include small access modifications, assistive technology, special computers, personal assistants, brailling, interpreters, etc. (Julie Reiskin, Colorado)

Following are the action proposals to the 105th Congress to address these needs.

Action Proposal 14: Reimburse Employers for Disability Expenses

Congress should institute a tax credit to reimburse employers for the expenses involved in providing employees with sign language interpreters, print materials in alternative formats, on-the-job personal assistance, extraordinary training, job coaches, and other accommodations that are not funded by other sources.

ADA specifies that many of these costs are reasonable expenses that individual employers should bear. According to hearing participants, employers do not agree that they should have to pay for these accommodations. Consequently, potential employers find ways to avoid hiring people who need such accommodations. NCD believes that to level the playing field for job applicants with disabilities, tax credits should be available to employers that bear accommodation expenses.

Action Proposal 15: Institute a Tax Credit for Disability/Diversity Training

Congress should enact tax credits for employers that conduct disability/diversity training for all personnel within the organization. The credit should be available only for 1 year after its establishment.

Many of the consumers at the Houston conference advocated for disability/diversity training for employers and their employees, conducted by professionals with disabilities. The consumers contended that such training could open employment doors for many with disabilities. It could help people get past the awkwardness and embarrassment they feel when they are around people with disabilities, the consumers said, by teaching them "disability etiquette" and by allowing them to find humor in overcoming their initial discomfort. Disability/diversity training could help people see those with disabilities as just one more part of an increasingly diverse workforce.

NCD believes that making this tax credit available for only 1 year would encourage employers to move quickly toward supporting disability awareness and a new focus on employing individuals with disabilities.

One Proposal Not Endorsed

The final form of many of the action proposals was substantially influenced by testimony given during the 13 hearings held around the country. NCD has decided not to endorse one proposal that had been included in the recommendations circulated before the hearings because of various objections raised by hearing participants.

Rejected Action Proposal: Create an Employer FICA Exemption

> Currently, employers are obligated to pay 7.65 percent of each employee's wages as a FICA contribution to Social Security and Medicare. Congress should create a FICA tax exemption for employers of employees with disabilities. During the 1st employment year, the employer could keep 50 percent of that FICA obligation. During the 2nd and 3rd years, the employer could keep 75 percent and 100 percent, respectively.

The idea behind the increasing exemption over the first 3 years was to use the tax exemption to encourage employers to keep employees until their training and experience made it economically unwise to replace them with new employees. The proposal provided that the exemption would not be available for employees with hidden disabilities unless the employee chose to self-disclose the disability. The original proposal suggested that an employee could use the FICA exemption as a bargaining chip with a potential employer.

The proposal for a FICA tax exemption proved to be very controversial at some of the hearings. Some people saw the FICA tax break as an unconscionable bribe, while others said that it would be a great tool to counter discrimination. Here is some of the testimony.

> *The idea of providing employers with some monetary benefits for hiring us flies in the face of how Americans see themselves these days. . . . A tax break, to the best of my understanding, would represent a bribe to both. . . . A tax break implies that the disabled person is not up to the job before proof to the contrary.* (Jon Crowder, Berkeley, California)

> *I do not want my disability to be used as a tax break for employers to save money; I want to be hired for me.* (Heidi Myhre, Minnesota)

> *By offering employer incentives, many people who are afraid to hire a person with a disability will realize some legitimate returns on their employees. This works on attitude through the pocketbook. I like it.* (Cheryl, personal assistant services coordinator at the Access Center of San Diego)

> *We noted with concern the recommendation that persons with disabilities use their willingness to disclose their disability (and thus qualify their employer for additional tax breaks) as a "bargaining chip" in their negotiations with employers. Our current research suggests that the issue of disclosure—particularly for people with psychiatric disabilities—is so fraught*

with tension and ambivalence that such a recommendation is inappropriate, and we would strongly urge NCD to remove that item from its document. (Richard Baron, director of Matrix Institute, Philadelphia)

Several Albuquerque participants expressed concern over the lack of employment opportunities and economic development in rural areas and on reservations. Employers, they said, need incentives to hire people with disabilities for the long term. One person thought the tax credit for hiring someone with a disability should last for 5 rather than 3 years. Another participant suggested that tax credits be given to employers for providing vocational rehabilitation, job coaches, and other support services.

After reviewing all this testimony, NCD concluded that the arguments for including an employer incentive such as the FICA exemption do not outweigh the concerns about "bribery" and self-disclosure, especially because the benefit to employers would be quite small except for very high-paying jobs. (The benefit to an employer of a full-time worker getting $5 per hour would be less than $400 the 1st year and $800 the 3rd year.) NCD therefore does not recommend the FICA exemption.

IN CONCLUSION

NCD firmly believes that hundreds of thousands of the millions of working-age SSI recipients and DI beneficiaries want to go to work and would do so except for the many barriers that still exist, despite the enactment of ADA.

Some of the barriers are financial. The action proposals dealing with health insurance and the SSA work incentives will, NCD believes, overcome the barriers that currently make it more advantageous financially to remain unemployed than to get a job.

Some of the barriers involve an employment service system that offers neither choice to consumers nor sufficient rewards to service providers. The NCD proposals would give consumers a choice of service providers that would readily accept the risk of helping individuals with severe disabilities. It also would give consumers access to funding for education, assistive technology, and business investments that could help them gain economic self-sufficiency and personal dignity.

Finally, some of the barriers concern employment opportunities. The proposals would allow employers to claim tax credits for the extra expenses they might incur in hiring someone with a disability. The proposals also would give employers an incentive to support training that might make it easier for them and their employees to integrate individuals with disabilities into their organizations.

In recent congressional testimony, GAO emphasized the need to take a holistic approach in dealing with return-to-work reforms. Citing a number of earlier studies, GAO said that to be effective, SSA must "develop a comprehensive, integrated, return-to-work strategy that includes (1) intervening earlier, (2) providing return-to-work supports and assistance, and (3) structuring benefits to encourage work."[17] NCD believes that the proposals incorporated in this report more than meet GAO's requirements. They not only would provide for intervening early, providing

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[17] Testimony before the Subcommittee on Social Security, Committee on Ways and Means, House of Representatives, July 23, 1997. *Social Security Disability: Improving Return-to-Work Outcomes Important, but Trade-offs and Challenges Exist.* GAO/T-HEHS-97-186.

supports, and restructuring benefits, but they also would deal with employer reluctance and the need for some consumers to start their own businesses.

NCD issues a challenge to the 105th Congress to tap into the potential provided by people who have disabilities. America's citizens with disabilities want very much to contribute to their country's continued preeminence in the world of nations. They have the talents and the capabilities to do so; and if the proposals presented in this report are enacted, they undoubtedly will.

APPENDIX

MISSION OF THE NATIONAL COUNCIL ON DISABILITY

Overview and Purpose

NCD is an independent federal agency led by 15 members appointed by the President of the United States and confirmed by the U.S. Senate.

The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act; as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.

- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on

individuals with disabilities, access to health care, and policies that operate as disincentives for individuals to seek and retain employment.

- Making recommendations to the President, the Congress, the Secretary of Education, the Director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies, respecting ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.

- Providing the Congress, on a continuing basis, advice, recommendations, legislative proposals, and any additional information that the Council or the Congress deems appropriate.

- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.).

- Advising the President, the Congress, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services within the Department of Education, and the Director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.

- Providing advice to the Commissioner with respect to the policies and conduct of the Rehabilitation Services Administration.

- Making recommendations to the Director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.

- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this Council for legislative and administrative changes to ensure that such recommendations are consistent with the purposes of the Council to promote the full integration, independence, and productivity of individuals with disabilities;

- Preparing and submitting to the President and the Congress an annual report titled *National Disability Policy: A Progress Report.*

- Preparing and submitting to the Congress and the President an annual report containing a summary of the activities and accomplishments of the Council.

International

In 1995, NCD was designated by the Department of State to be the official contact point with the U.S. government for disability issues. Specifically, NCD interacts with the special rapporteur of United Nations Commission for Social Development on disability matters.

Consumers Served and Current Activities

While many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, it was NCD that originally proposed what eventually became ADA. NCD's present list of key issues includes

improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology, and ensuring that persons with disabilities who are members of minority groups fully participate in society.

STATUTORY HISTORY

NCD was initially established in 1978 as an advisory board within the Department of Education (Public Law 95-602). The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed NCD into an independent agency.

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